

# Parenting a child with Autism Spectrum Disorder: Challenges, Coping Strategies, and WHO Resolution on Autism disorder.

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*Abstract— The present qualitative research explores the real-life events and problems that parents confront when raising children with Autism Spectrum Disorder (ASD) It investigates the strategies for coping adults use to overcome these hurdles, demonstrating their incredible endurance. The investigation uses Bronfenbrenner's Ecological Systems Theory and Goffman's Labelling Theory to deeper comprehend the environmental impacts on parents' perspectives. The study included parents, predominantly moms aged between 30 and 40 years old from different socioeconomic groups. The study recruited individuals via accidental and purposive selection strategies. The acquired data was analysed using thematic evaluation with expressed permission. The problem's challenges included navigating information and awareness, gaining access to help and resources, and making emotional and practical adjustments. Parents used strategies for coping.*

*Index Terms— Autism, Autism Disorder, Challenges and Strategies to Cope up, Autism, ASD, Autism Spectrum Disorder, Children, COVID-19, Testing, Vaccination, Neurotropism, SARS-CoV-2*

## I. INTRODUCTION

Supporting children's of parents with Autism Disorder Unexpectedly, the investigation found an adverse connection between anxiety and moms who used involvement coping techniques and had a network of social support groups. This highlights the significance of strengthening these ways of coping to reduce stress for women parenting kids who have ASD. (Rudy, 2022)Almost every aspect of shut-downs and quarantines can undermine the systems that autistic people and their caregivers have set up. For example:

Interrupted Schedule: For autistic persons, consistency and regularity are critical. Even little deviations in regularity (a school putting together, a sudden shift in weather) may prove stressful. COVID-19 can disturb

every person's schedule, resulting in missed activities or cancelled programmes. Disruptions may make living harder for autistic individuals.

Therapeutic Complications: Autistic persons generally get many types of therapy, including words, professional, behavioural, social, behavioural, and/or psychiatric..

Eating Habits: Many autistic persons are quite fussy about what they eat. People may consume only a few items or only particular brands of food. Sometimes supply chain interruptions might make it difficult to find a particular food item or brand. A shortage of common foods can be very upsetting for autistic persons.

Limited Contact: Autistic persons rely on connections with certain instructors, therapists, family members, and caretakers. When communication with such persons is restricted, as it was throughout the COVID-19 epidemic, tension and behavioural issues may develop.

Lack of interaction: Some autistic persons reside in environments other than their own homes (such as group homes). Some establishments have to limit access because of COVID-19, that might cause discomfort. (Autism, 2023)

## II. RESEARCH QUESTIONS

Specifically, the study aims to shed light on the following questions:

1. What is Autism?
2. What are the problems faced by Parents of Autistic child?
3. What are the strategies involved in raising a autistic Child?

#### 4. Effects of Covid -19 on children with Autism.

The COVID-19 pandemic had a significant influence on numerous families and patients in the autistic community, particularly the complicated care of autism-related diseases amid the entire lockdown. While the total lockdown, kids who had autism struggled to adjust to a disruption in routine, because of the absence of access to customised educational resources, restricted personal space, and nutrition and sleep issues. Furthermore, children with autism or intellectual limitations are more likely to be exploited by others during the pandemic since traditional community services are discontinued working to safeguard them. (Mohammed Al-Beltagi, 2022) The lockdown has a significant negative impact on sensory-motor development, cognitive ability, sleep, morale, behaviour, and interactions with others, potentially affecting approximately 50% of children with special needs. Children with autism should be given priority when it comes to COVID-19 testing and treatment.

##### Causes

Available scientific research reveals that several variables, including both genetic and environmental factors, increase a child's risk of developing autism. A comprehensive investigation utilising a number of approaches over a long time has shown that the measles, rubella, and mumps vaccination is not linked to autism.

Other childhood immunisations are likewise not linked to an increased risk of autism, according to evidence. Extensive study investigating the preservative thiomersal and the adjuvant aluminium found in some inactivated vaccines has shown that these components in children vaccines do not raise the incidence of autism. (Saeed NK, 2021)

Assessment and Care Autistic individual growth, health, well-being, and quality of life can be improved by a variety of treatments beginning in early childhood and continuing throughout their lives. Early access to evidence-based psychosocial therapies can help autistic youngsters speak better and interact socially. Child growth monitoring should be incorporated into standard maternal and child health care.

Once autism has been identified, it is critical that kids, teens, and adults with autism, as well as their carers, get the appropriate knowledge, resources, referrals, and practical support based on their particular and changing desires and requirements.

People with autism have complicated healthcare requirements that necessitate a variety of integrated services, including health promotion, treatment, and rehabilitation (World, 2023).

##### Psychometric Test

The Ritvo Autism Asperger Diagnostic Scale-Revised (RAADS-R) was created to identify autistic persons who "evade diagnosis" because of subclinical symptoms of autism (typically due to their capacity to disguise autistic inclinations). Our Autism test is based on the Broad Autism Phenotype Questionnaire, which is intended to assess the manifestation of autistic characteristics in adults. This test is not meant to be used as a diagnosing tool; rather, it is provided for educational purposes only. Our Autism exam consists of 36 multiple-choice questions and takes just over five minutes for everybody to finish. The results of this examination do not constitute a diagnosis, but rather emphasise a tendency towards (or against) habits commonly associated with autism, which include: a lack of enthusiasm or pleasure in communicating with others, lack of enthusiasm in change or problems adapting to a new environment, and difficulties in social elements of language. (embrace Autism)

Insomnia in school-age children with Asperger syndrome or high-functioning autism

Asperger syndrome (AS) and high-functioning autism (HFA) are pervasive developmental disorders (PDD) in individuals of normal intelligence. Childhood AS/HFA is considered to be often associated with disturbed sleep, in particular with difficulties initiating and/or maintaining sleep (insomnia). However, studies about the topic are still scarce. The present study investigated childhood AS/HFA regarding a wide range of parent reported sleep-wake behaviour, with a particular focus on insomnia.

### III. METHODS

Sleep and related behavioural features were studied between different gender matched normally growing children AS/HFA children aged 8 to 12 years old. Several elements of sleep-wake behaviour, particularly insomnia, were assessed using a standardised paediatric sleep questionnaire, in which parents described their children's sleep habits over the six months preceding this one. Recent sleep habits were tracked using a one-week data diary and actigraphy. Behavioural features were evaluated using material gathered from parent and teacher judgements in the High-Functioning Autism Spectrum Screening Questionnaire and the Strengths and Difficulties Questionnaire. The shareable link to the given article is as follows: <https://rdcu.be/dC1mi>.

#### IV. RESULTS

Parent-reported difficulty beginning sleep and daytime drowsiness were more prevalent in children with AS/HFA than in controls, and 10 of 32 children with AS/HFA (31.2%) met our diagnostic of child insomnia, whereas none of the controls did. The parent-reported sleeplessness was consistent with the actigraphy results. Children with sleeplessness showed higher parent-reported autistic and emotional symptoms, as well as more teacher-reported behavioural and hyperactive symptoms, than kids whom did not have insomnia.

#### CONCLUSION

Parental reports indicate that in childhood AS/HFA insomnia is a common and distressing symptom which is frequently associated with coexistent behaviour problems. Identification and treatment of sleep problems need to be a routine part of the treatment plan for children with AS/HFA

How can Parents handle stress ?

Many aspects of autism, including as tantrums, anger, language deficiencies, restricted family possibilities, and incapacity to achieve independence, contribute to the profound and particular pain that many carers endure.

Families might experience loss, despair, rage, and frustration. They may fear for their own and their children's safety. Coordinating health care institutions

and insurance organisations on a regular basis takes a lot of time, energy, and money, which can lead to tiredness and monetary strain.

To handle these hurdles, parents should explore and use any and all resources accessible to them. They might rely largely on their family and friends for assistance. If carers begin to experience anxiety or sadness, they should seek professional support. Finding a support group near you is vital, because its members may give understanding, emotional strength, and critical

Strategies on Parenting a child on Autism Spectrum  
See the Positive: Reinforcement that is positive works effectively for children with autism spectrum condition, just like it does for everyone. That implies that praising them for excellent behaviours will make them (and you) happy. Be detailed so that they understand what you enjoyed about their behaviour. Find methods of recognising them, whether through additional playtime or a modest incentive such as a sticker. Also, as with everyone, whether on the spectrum or not, value your kids for what they truly are. As a carer, you must love your child for who they are. (Psy)

Get along with Support Groups: Although there are multiple internet resources for knowledge, you may still feel isolated. That explains why it is critical to find a support network in your area to connect with.

Organise Autistic Records: Keeping organised records of your child's medical appointments will assist you build a full picture of how they are doing at various stages. You might also wish to write notes on improvements, and medical statuses.

Build Connection with your child: Connect with your kid in whatever manner you can, such as by chatting, reading, or displaying instructional films, even if it appears that the youngster is not paying attention. Read what other parents and autistic adults have written.

Medical Insurance Can Help to Some Extent  
Insurance covers many, but not all, amenities for children with autism. All 50 states currently mandate commercial insurance policies offer some form of

reimbursement for autism therapy. Most Insurance plans pay Applied Behavioural Research when it is judged medically essential. However, insurance companies may not cover all of the costs or the duration of care that a kid requires.

Individuals with autism are eligible for academic assistance via the public school system. They may create an individualised learning plan or a 504 plan, two of which aim to ensure that children fully engage in what they are learning.

Attending a support group in your neighbourhood may be incredibly beneficial for parents of autistic children. Members not only provide emotional backing, but they are also knowledgeable about the programmes accessible in their state. (Marriott, 2021)

#### Genetic susceptibility to environmental triggers

Autism is hypothesised to result from a complex combination of many and varied genetic genes, epigenetic modifications, and external factors. Many people think that autism develops when a biologically sensitive youngster gets subjected to an ecological trigger. Studies into the pathophysiology of autism shows various probable pathways, which further supports the probability of diverse types of autism.

#### Treatment

The numerous personal experiences of hope with early intervention are being confirmed by research indicating significant changes in the brain throughout early development and outstanding results from various early educational and behavioural intervention courses. As a result, systematic screening and diagnostic examination of youngsters displaying early indicators of the condition, as well as further research focusing on early detection, are critical steps towards an improved outcome.

Early warning signs Current diagnostic tools (ICD-10, World Health Organisation, 1993; DSM-IV, American Psychiatric Association, 1994) require that the disorder begin before the age of three. Autism is currently diagnosed in the third or fourth year in nuclear instances, and much sooner in atypical or mild forms of autism. Diagnostic tools [e.g., Childhood Autism Rating Scale (Schopler et al., 1988) and Autism Diagnostic Interview—Revised (Lord et al.,

1994)] are based on extensive clinical interviews with carers and record taking, with an emphasis on early childhood. Abnormalities may be detected when the diagnosis is made late. The latest development in early diagnosis is the deployment of experimental tests for screening to detect autism at 18 months. Preliminary research, both with biologically at risk Babies (Baron-Cohen et al., 1992) and population tests (Baron-Cohen et al., 1996) indicate that failing to display imaginative play and cooperative focus at 18 months singles out children diagnosed with autism at 30 months (Charman, 1994). Other research, both prospective and retrospective, reveals that before the age of 18 months, infants with autism do not exhibit clearly identifiable social or cognitive deficits (Lister, 1992; Johnson et al., 1992). Interest in this field of study remains high, with household video analysis serving as one source of knowledge (Osterling and Dawson, 1994).

#### Recent advances in the genetics of autism spectrum disorder: the impact of whole-exome sequencing

Mendelian genetic diseases have been treated using traditional gene mapping procedures, such as candidate gene investigations and directional cloning strategies. Since 2005, next-generation sequencing (NGS) technologies have evolved into quick, a high-through, and cost-effective alternatives to meeting medical science and research demands [163]. Whole-exome sequencing (WES) was recently used to detect unusual or new genetic abnormalities in hereditary illnesses. Whole exome sequencing is a type of genomic sequencing done with the blood or saliva. Whole exome sequencing is a sort of DNA sequencing that is becoming more frequently utilised to determine the cause of ailments or diseases. Genetic testing is widely used in some health domains, such as cancer diagnosis and prenatal screening. Recent significant advancements in whole exome sequencing (WES) allow for quick Investigation of ASD-associated variants, such as single nucleotide variations (SNVs) and indels.

#### Social communication

Autistic persons have difficulty comprehending verbal and nonverbal communications, such as gestures or tone of voice. Some autistic persons cannot talk or have limited communication, whilst others have excellent language abilities but struggle to interpret

sarcasm or tone of voice. Other issues include taking things literally, not grasping complex concepts, needing extra time to digest information, and repeating what people say (known as echolalia).

#### Social interaction

- Autistic persons frequently struggle with 'reading' individuals, which is detecting or comprehending one's emotions and intentions, as well as articulating their own. This may render it difficult to negotiate the social environment. Autistic individuals may exhibit insensitivity, prefer alone when overburdened, avoid seeking comfort from others, exhibit unusual or inappropriate behaviour, and struggle to make connections. •With these unwritten laws, the world might appear unexpected and confusing to autistic individuals. This is why they typically choose patterns in which they are aware of what is going to occur. They might want to commute exactly the same way to and from their school or employment, and dress the same clothing, consume precisely the identical thing in the morning.
- Autistic individuals may exhibit repetitive motions, such as hand flapping, rocking, or using objects repeatedly, such as spinning pens or opening and closing doors. Autistic persons frequently participate in these actions to help them relax when they are upset or nervous, but many also do it because they like it.
- Autistic individuals may experience difficulty and anxiety when their routine changes. It might be having to adjust to significant events like Christmas or transferring schools, confronting uncertainty at employment, or even smaller like the bus diversion that can cause individuals worry. It might be trying to adjust to significant occasions like Christmas or transferring schools, facing uncertainty at work, or anything smaller like a public transportation diversion that may give individuals worry.
- Autistic individuals who are intensely concentrated might excel intellectually and in the job. However, this can lead to disregard of other elements of our lives. Anxiety is a major issue for many autistic individuals, especially in contexts of society or when confronting change. Autistic

individuals as well as their loved ones may have psychological and physical effects, affecting their overall quality of life. It is critical that autistic persons learn to identify their motivating factors and develop methods of coping to alleviate their nervousness. However, most autistic persons struggle to recognise and regulate their feelings. Over one-third of autistic persons suffer from major psychological concerns, and mental health services fail far too many of them.

- Autistic individuals may experience meltdowns or shutdowns when faced with overwhelming situations. These are really intense and demanding experiences.

A meltdown occurs when a person is utterly overpowered by their present situation and briefly loses behavioural control. This lack of control can manifest itself verbally (e.g., yelling, weeping), physically (e.g., kicking, lashing out, biting), or both. Meltdowns in children are sometimes misinterpreted as temper tantrums, and parents and their autistic children face unpleasant comments and judgmental looks from fewer empathetic members of the public.

A shutdown seems less severe to the outer world, yet it can be as debilitating. Shutdowns are also a reaction to being stressed out, although they may look more passive, such as an autistic person being silent or 'switching off'. One autistic woman described experiencing a shutdown as: 'just as disheartening as a breakdown, because of neither being able to determine out how to respond how one wishes to, or not knowing able properly engage at all; there doesn't seem any 'figuring out' since the mind feels like it has passed the point of being able to comprehend.'

#### Assessment and care

Optimal growth, well-being, and quality of life for autistic individuals can be achieved through a variety of therapies from early childhood to adulthood. Early access to evidence-based psychological treatments can help autistic youngsters speak better and interact socially. Child growth monitoring should be incorporated into standard maternal and child health care.

- Once autism has been identified, it is critical that children, adolescents, and adults with autism, as

well as carers, get appropriate knowledge, resources, referrals, and practical assistance based on their particular and changing desires and requirements.

- Individuals with autism have complicated healthcare requirements that necessitate a variety of integrated services, including prevention, treatment, and recovery. Partnership with the
- It is necessary to include the healthcare industry as well as other industries, including schooling, work, and social care.
- Measures for individuals with autism and developmental impairments should be created and implemented with their cooperation. Healthcare must be supplemented by social and social measures that promote availability, inclusion, and engagement. (World, 2023)

Treatments for persons with autism and other developmental problems must be developed and put into effect in collaboration with those affected. Care must be supplemented by neighbourhood and social measures that promote availability, inclusion, and assistance.

#### Human rights

Everyone, including those with autism, is entitled to the best possible physical and mental health. Nonetheless, autistic persons frequently face stigma and prejudice, including arbitrary restriction of health care, education, and chances to engage and take part in their communities. People with autism face the same illnesses as ordinary people. However, they might face additional healthcare demands due to autism or other concurrent illnesses. They could be more sensitive to collecting noncommunicable chronic illnesses due to behavioural risk factors such as lack of exercise and poor food habits, as well as being more exposed to aggression, injury, and abuse. People with autism, like the remaining members of the population, require access to mainstream health-care services.

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care, education, and chances of getting involved and take part in their surroundings. Individuals with autism face the identical health issues as ordinary people. But they may have additional health-care demands due to autism or other that occur together illnesses. They may be more sensitive to acquiring noncommunicable chronic illnesses due to behavioural risk factors such as physical inactivity or poor food habits, as well as being especially susceptible to aggression, injury, and assault. People with autism, like a majority of the population, require the availability of general medical care.

People with autism, like the remainder of humanity, require access to general medical care, including promotional and preventive treatments, as well as treatment for chronic and acute illnesses. Nonetheless, autistic persons have a larger proportion of unmet health-care demands than the overall population. They are additionally more exposed to emergencies involving humanity. A major hurdle is a lack of awareness and comprehension of autism among healthcare practitioners.

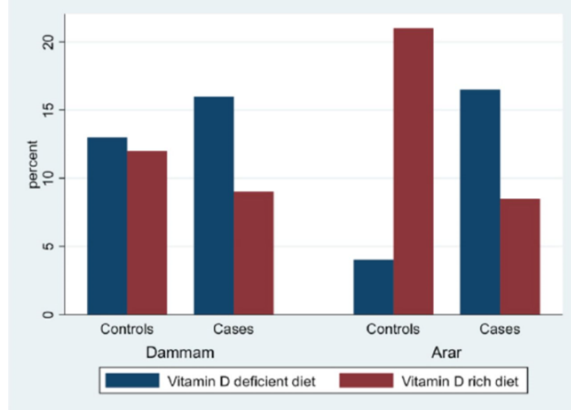
#### WHO resolution on autism spectrum disorders

In May 2014, the Sixty-seventh World Health Assembly passed a resolution titled Comprehensive and coordinated efforts for the management of autism spectrum disorders, (Organisation, 2014). Downloads\comprehensive and coordinated efforts of management of autism spectrum disorder.pdf which was supported by more than 60 countries.

The resolution urges WHO to collaborate with Member States and partner organisations to strengthen national capacity to address ASD and other developmental disabilities.

A case control study was conducted and the data was collected from September 2017 to December 2017 by interviewing the parents of 100 Saudi autistic children and 100 normal children aged 3-10 years from Arar and Dammam. A specially designed questionnaire was used to collect the data which includes socio-demographic characteristics of the parents and antenatal history of the mother and developmental history, social history and dietary habits of the child. To find out the association between environmental factors and

development of autism in children, logistic regression with odds ratio used. (Anitha Oommen, 2023)



Vitamin D rich diet

Researchers have reported Vitamin D deficiency in Saudi children.<sup>23</sup> A group of researchers found that Vitamin D deficiency was higher in autistic children when compared to healthy children. Results showed that Vitamin D rich diet may protect the children from developing autism.

In many studies, maternal and paternal age older than or equal to 34 years were found to be associated with increased risk of autism in their offspring. Researchers who studied the risk of autism with older reproductive age concluded that maternal age is an important factor in the development of autism. Figure 1: Percentage of Vitamin-D rich food consumption of autism. In conclusion, in our study, the significant environmental factors which could contribute to the development of autism were consanguineous marriage, inadequate family income, medications taken by the mother during pregnancy, vitamin D deficient diet of the child and increased maternal age during pregnancy. More in depth studies with larger sample size are needed to assess the role of environmental factors like artificial food additives, chemical poisons in toys, use of i-pads by children, television watching, parental conflict and emotional state of the mother in the development of autism. (Anitha Oommen, 2023)

- WHO and its partners recognise the need to increase nations' capacity to support the optimal health and well-being of all persons with autism. WHO aims to improve the quality of life for persons with autism by boosting government dedication and action.

- Advising on autism regulations and action plans within the context of health, mental and brain wellness, and disabilities.
- Improving the health workforce's ability to offer appropriate care and encourage optimal well-being and well-being for people with autism.
- Encouraging inclusive and enabling environments for people with autism and other developmental disabilities, and providing support.
- Providing advice on autism laws and strategies within the context of health, mental and brain health, and disabilities. Increasing the medical staff in order to deliver suitable treatment and encourage the best possible condition of individuals with autism. promoting welcoming and enabling environments over people with autism in addition to developmental disorders alongside offering support.
- The WHO Comprehensive Mental Health Action Plan 2013-2030 and World Health Assembly Resolution WHA73.10 for "global actions on epilepsy and other neurological disorders" call on countries to address the current significant gaps in early detection, treatment, care, and recovery for mental illness and neurologically developed conditions, including autism. It also encourages counties to take care of the socioeconomic, educational in nature, and inclusiveness needs of persons with psychological and neurological ailments and their relatives, as well as to strengthen monitoring and relevant study. (Worht)
- It also encourages counties to address the social, economic, educational, and inclusion needs of persons with mental and neurological diseases and their families, as well as to strengthen monitoring and relevant research. (Worht)

## CONCLUSION

The most recent advancements in autism genomics reveal the startling intricacy of the condition's fundamental pathophysiology. High-throughput molecular screens, such as high resolution array-CGH, whole-exome and whole-genome sequencing, and transcriptome analysis, are likely to contribute to an improved awareness of the molecular causes of ASD. Rare genetic variations have been linked to autism in certain cases. However, diagnosing autism spectrum

disorder (ASD) is challenging due to the lack of a reliable test. Boosting public and medical personnel awareness of the ASD spectrum is critical as it encourages parents of ASD children to seek screening and diagnosis from a specialist, resulting in improved detection and therapy. Autism - Also

- Autism, often known as autism spectrum disorder, is a range of diseases that affect brain development.
- Approximately 1 in 100 children have autism.
- Autism is generally not diagnosed until late childhood, despite early detection of symptoms.
- The talents and needs among autistic persons differ and might change as they develop. While individuals with autism may live on their own others have significant difficulties and need constant care and assistance.
- Evidence-driven psychosocial therapies can enhance communication and social skills, enhancing the general well-being and standard of life for autistic individuals and their carers.
- Autism care requires societal and social activities to improve mobility, inclusion, and assistance.

One study showed that supplementation with vitamin D and tryptophan among pregnant women is an affordable method for preventing ASD among children . Similarly, another study showed that taking iron during pregnancy reduces the risk of developing autism. Other risk factors for having autistic children are a relative's marriage and advanced maternal age

Autism spectrum disorder (ASD) is a developmental disorder. It is recognized as impairing socialization and communication and causing frequent and restricted unusual behaviors . The prevalence of children diagnosed with ASD is increasing .Many factors can contribute to the rise in ASD diagnoses, such as modern diagnostic measurements and specialized diagnostic tools. However, it is not clear whether detection and reporting have improved or whether the number of reported cases has risen.

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